

1 CABINET FOR HEALTH SERVICES

2 Commission for Children with Special Health Care Needs

3 Health and Development Division

4 911 KAR 2:120. Kentucky Early Intervention Program evaluation and eligibility.

5 RELATES TO: 34 CFR 303, 20 USC 1471-1485

6 STATUTORY AUTHORITY: KRS 194A.030(7), 194A.050, 200.650-676, 34 CFR  
7 303.322, 20 USC 1473

8 NECESSITY, FUNCTION, AND CONFORMITY: The Cabinet for Health Services  
9 is directed by KRS 200.650 to 200.676 to administer funds appropriated to implement  
10 provisions, to enter into contracts with service providers, and to promulgate  
11 administrative regulations. This administrative regulation establishes the provisions for  
12 evaluation and eligibility policies pertaining to First Steps, Kentucky's Early Intervention  
13 Program.

14 Section 1. Evaluation. (1) A child referred to the First Steps Program shall be  
15 initially evaluated to determine eligibility. Until exiting the program and in accordance  
16 with subsection (8) of this Section, the child shall be evaluated on an annual basis to  
17 determine ongoing eligibility and to evaluate progress while in the program.

18 (2)(a) A determination of initial eligibility pursuant to Section 2 of this administrative  
19 regulation, assessments in the identified area of delay, in accordance with 911 KAR  
20 2:130, and the initial IFSP team meeting shall occur within forty-five (45) calendar days  
21 after a point of entry receives an initial referral; or

1 (b) If a determination of initial eligibility, assessments and initial IFSP team meeting  
2 does not occur within forty-five (45) calendar days due to illness of the child or a request  
3 by the parent, the delay circumstances shall be documented.

4 (c) If a family is referred for a determination of initial eligibility and the family is  
5 under court order or a social services directive to enroll their child in First Steps, the  
6 court or social service agency shall be informed within three (3) working days by the  
7 initial service coordinator, if the family refuses the determination of eligibility.

8 (3) Child records of evaluations transferred from an in-state or out-of-state  
9 developmental evaluator shall be reviewed by the initial service coordinator and shall be  
10 utilized for eligibility determination if:

11 (a) The records meet First Steps evaluation time lines established in subsection  
12 (4)(a) of this section; and

13 (b) The records contain the developmental evaluation information established in  
14 subsection (10)(a) and (b) of this section.

15 (4) The primary level evaluation is the first level in the First Steps evaluation  
16 system that shall be utilized to determine eligibility, developmental status and  
17 recommendations for further assessment to determine program planning.

18 (a) If there is a previous primary level evaluation available, it shall be used to  
19 determine eligibility if:

20 1. For children under twelve (12) months of age, the evaluation was performed  
21 within three (3) months prior to referral to First Steps; or

22 2. For children twelve (12) months to three (3) years of age, the evaluation was  
23 performed within six (6) months prior to referral to First Steps; and

1           3. There is no additional information or the family has not expressed new concerns  
2 that would render the previous evaluation no longer valid.

3           (b) If there is a previous primary level evaluation available that was performed  
4 within the timeframes established in subparagraphs 1 or 2 of this paragraph but there  
5 are new concerns that shall render the evaluation no longer valid, the initial service  
6 coordinator shall request a new primary level evaluation.

7           (c) Primary level evaluations shall provide evaluation in the five (5) developmental  
8 areas identified in Section 2(1)(c)1. through 5. of this administrative regulation using  
9 norm-referenced standardized instruments that provide a standard deviation score in  
10 the total domain for the five (5) areas;

11           (d) The primary level evaluation shall be provided by a physician or nurse  
12 practitioner and a primary evaluator approved by the cabinet;

13           (e) A primary level evaluation shall include:

14           1. A medical component completed by a physician or a nurse practitioner that shall  
15 include:

16           a. A history and physical examination;

17           b. A hearing and vision screening; and

18           c. A child's medical evaluation that shall be current in accordance with the EPSDT  
19 periodicity schedule.

20           2. A developmental component completed by a cabinet-approved primary level  
21 evaluator that utilizes norm-referenced standardized instruments, the results of which  
22 shall:

23           a. Include the recommendation of a determination of eligibility or possible referral

for a record review; and

b. Interpreted to the family prior to the discussion established in subsection (5) of this section.

(5) Prior to the initial IFSP team meeting the initial service coordinator shall:

(a) Contact the family and primary level evaluator to discuss the child's eligibility in accordance with subsection (4)(e)2.b. of this Section. If the child is determined eligible, the service coordinator shall:

1. Make appropriate arrangements to select a primary service coordinator;

2. Arrange assessments in the areas identified in Section 2(1)(c) found to be delayed; and

3. Assist the family in selecting service providers in accordance with 911 KAR 2:110. If the child is receiving therapeutic services from a provider outside of the First Steps Program, the service coordinator shall:

a. Invite the current provider to be a part of the IFSP team;

b. Request that the provider supply the team with his assessment and progress reports; and

c. If the current provider does not want to participate, have the First Steps provider consult with the current provider if assessing the area being treated by the current provider; and

(b)1. If the child does not have an established risk condition identified in Section 2(1)(c) of this administrative regulation, and is determined not eligible, the team shall discuss available community resources, such as Medicaid, EPSDT, The Department for Public Health's and the CCSHCN's Title V programs, and other third-party payors.

1           2. If the child has an established risk condition, and the developmental evaluation:

2           a. Does not indicate a developmental delay in at least one skill area, the family  
3 shall receive service coordination services until the earlier of:

4           (i) An annual developmental evaluation is performed in accordance with subsection  
5 (8)(d) of this administrative regulation; or

6           (ii) The family has a concern or suspects that the child may have a delay present  
7 that was not revealed by the testing.

8           b. If the situation described in clause (ii) of this subparagraph occurs, the  
9 procedure established in Section 2(1)(d)3. of this administrative regulation shall be  
10 followed.

11          (6) At the initial IFSP team meeting the IFSP team shall:

12          (a) Include the following members at a minimum:

13           1. The parent of the child;

14           2. Other family members, as requested by the parent, if feasible to do so;

15           3. An advocate or person outside of the family, if the family requests that the  
16 person participate;

17           4. The initial service coordinator;

18           5. The primary service coordinator;

19           6. A provider who performed an assessment on the child;

20           7. If appropriate, a First Steps provider who shall provide services to the child or  
21 family;

22          (b) Verify the child's eligibility;

23          (c) Review the evaluation information identified in subsection (4) of this section;

1 (d) Review the assessment reports in accordance with 911 KAR 2:130;

2 (e) Determine the family's outcomes, strategies and activities to meet those  
3 outcomes; and

4 (f) Determine the services the child shall receive in order for the family to learn the  
5 strategies and activities identified on the IFSP. This shall include identifying:

6 1. The discipline;

7 2. The professional, paraprofessional, or both;

8 3. The method in which services shall be delivered, such as individual, group, or  
9 both; and

10 4. The payor source for the service.

11 (7)(a) Reevaluations shall be provided if the IFSP team determines a child's  
12 eligibility warrants review.

13 (b) Primary level reevaluations shall not be used to:

14 1. Address concerns that are medical in nature; or

15 2. Provide periodic, ongoing follow-up services for post testing or testing for  
16 transition.

17 (c) Based on the result of the reevaluation or annual evaluation, the IFSP team  
18 shall:

19 1. Continue with the same level of services;

20 2. Continue with modified services; or

21 3. Transition the child from First Steps services.

22 (8) In accordance with KRS 200.664(7), in order to determine ongoing eligibility;

23 (a) A developmental evaluation shall be performed on an annual basis no earlier

1 than ninety (90) days nor later than sixty (60) days before the annual IFSP expiration  
2 date; and

3 (b) An updated medical evaluation shall be obtained from the child's physician or  
4 nurse practitioner in accordance with subsection (4)(e)1.c. of this Section.

5 (c) The annual developmental evaluation shall be performed by a primary level  
6 evaluator who is not currently providing a therapeutic intervention for that child and shall  
7 provide an evaluation in the five (5) developmental areas identified in Section 2(1)(c) of  
8 this administrative regulation.

9 (d) If the results of the annual evaluation do not meet the eligibility requirements of  
10 Section 2(1)(d) or (f) of this administrative regulation, within three (3) days of receiving  
11 the written evaluation report, the service coordinator shall:

12 1. Notify the service provider that the child and family are no longer eligible for First  
13 Steps services; therefore, therapeutic intervention shall cease;

14 2. Facilitate a transition conference in accordance with 911 KAR 2:140, Section 14;  
15 and

16 3. Subsequent to the transition conference, discharge the child from the program.

17 (9) A review of the child's First Steps record shall be the second level in the First  
18 Steps evaluation system that shall be utilized to determine eligibility, medical or mental  
19 diagnosis, program planning, or plan evaluation.

20 (a) Upon obtaining a written consent by the parent, a service coordinator shall  
21 submit a child's record to the CCSHCN for a record review if:

22 1. A primary evaluator identifies a need for further developmental testing  
23 necessary to clarify a diagnosis to further define the child's developmental status in

1 terms of a child's strengths and areas of need;

2 2. A child does not meet eligibility guidelines at the primary level, but an IFSP team  
3 member and the family still have concerns that the child is developing atypically and a  
4 determination of eligibility based on professional judgment is needed; or

5 3. The IFSP team requests an intensive level evaluation for the purposes of  
6 obtaining a medical diagnosis or to make specific program planning and evaluation  
7 recommendations for the individual child.

8 (b)1. If a service coordinator sends a child's record for a record review, the  
9 following shall be submitted to the Record Review Committee, Louisville CSHCN  
10 office at 982 Eastern Parkway, Louisville, Kentucky 40217:

11 a. A cover letter from the service coordinator or primary evaluator justifying the  
12 referral for a record review;

13 b. Primary level evaluation information specified in subsection (10) of this section;

14 c. Available assessment reports required in 911 KAR 2:130;

15 d. Available IFSPs and amendments;

16 e. Most recent progress reports from the IFSP team members. Reports older than  
17 three (3) months shall include an addendum reflecting current progress;

18 f. Therapeutic staff notes from the previous two (2) months; and

19 g. If requesting a record review for a child who is receiving speech therapy, a  
20 hearing evaluation performed by an audiologist within six (6) months of the request.

21 2. The service coordinator requesting the record review shall attempt to procure  
22 and submit the following information, if available:

23 a. Birth records, if neonatal or perinatal complications occurred;



- b. General pediatric records from the primary pediatrician;
  - c. Medical records from hospitalizations; and
  - d. Records from medical subspecialty consultations, such as neurology, orthopedic, gastroenterology or ophthalmology.
- (c)1. Upon receiving a referral, a team of CCSHCN professional staff shall conduct a record review.
  2. After conducting the record review, CCSHCN staff shall:
    - a.(i) Determine that there are at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age;
    - (ii) Determine if further developmental testing, diagnostics or additional professional judgment are required in order to adequately ascertain the child's developmental needs; and
    - (iii) Refer the child for an intensive level evaluation, the third level in the First Steps evaluation system; or
    - (iv) Refer the family to local community resources; and
    - (v) Provide the IFSP team with recommendations for service planning; or
  - b.(i) Determine that there are not at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age; and
  - (ii) Provide the IFSP team with recommendation for transition planning;
  - c. Determine that the child meets or does not meet the eligibility criteria established in Section 2(1) of this administrative regulation; or
  - d. Provide the IFSP team with recommendations for service planning.
  - (d) Upon request of the CCSHCN, a team approved by the CCSHCN and

consisting of the following members shall perform an intensive level evaluation:

1. A board certified developmental pediatrician;

2. A pediatrician who has experience in the area of early childhood development;

3. A pediatric physiatrist; or

4. A pediatric neurologist; and

5.a. One (1) or more developmental professionals identified in 911 KAR 2:150, Section 1; or

b. If an IFSP is currently in place, a developmental professional representing each discipline that is currently on the IFSP in addition to a professional whose scope of work addresses additional concerns expressed by the Intensive Level Evaluation team.

(10) Family rights shall be respected and procedural safeguards followed in providing evaluation services:

(a) Written parental consent shall be obtained before conducting an evaluation or assessment by the evaluator or assessor respectively.

(b) If a parent or guardian refuses to allow a child to undergo a physical or medical examination for eligibility because of religious beliefs:

1. Documentation shall be obtained in the form of a notarized statement. The notarized statement shall be signed by the parent or guardian to the effect that the physical examination or evaluation is in conflict with the practice of a recognized church or religious denomination to which they belong.

2. If a child is determined to be eligible, First Steps shall provide, at the parent's request, services that do not require, by statute, proper physical or medical evaluations.

3. The initial service coordinator shall explain to the family that refusal due to

religious beliefs may result in a denial of services which require a medical assessment on which to base treatment protocols.

(11) A report shall be written upon completion of an evaluation.

(a) A record review report shall include the components specified in this paragraph that can be addressed without having the child or parent present for the evaluation. A report resulting from a primary level evaluation or an intensive level evaluation shall include the following components:

1. Date of evaluation;

2. Names of evaluators and those present during the evaluation, professional degree, and discipline;

3. The setting of the evaluation;

4. Name and telephone number of contact person;

5. Identifying information that includes the:

a. Child's CBIS identification number;

b. Child's name and address;

c. Child's chronological age (and gestational age, if prematurely born) at the time of the evaluation;

d. Health of the child during the evaluation;

e. Date of birth;

f. Date of evaluation;

g. Referral source; and

h. Reason for referral or presenting problems.

6. Tests administered or evaluation procedures utilized and purpose of instrument.

No one (1) method of evaluation shall be used, but a combination of tests and methods shall be used;

7. Test results and interpretation of strengths and needs of the child;

8. Test results reported in standard deviation pursuant to subsection (4)(e)2 of this section;

9. Factors that may have influenced test conclusions;

10. Eligibility;

11. Developmental status or diagnosis;

12. Suggestions regarding how services may be provided in a natural environment that address the child's holistic needs based on the evaluation;

13. Parent's assessment of the child's performance in comparison to abilities demonstrated by the child in more familiar circumstances;

14. A narrative description of the five (5) areas of a child's developmental status;

15. Social history;

16. Progress reports, if any, on the submitted information; and

17. A statement that results of the evaluation were discussed with the child's parent.

(b) The report established in paragraph (a) of this subsection shall be written in clear, concise language that is easily understood by the family.

(c)1. The reports and notification of need for further evaluation shall be made available to the current IFSP team and family within fourteen (14) calendar days from the date the evaluator received the complete evaluation referral.

2. In addition to the requirements established in this Section, an intensive level

1 evaluation site shall:

2 a. Provide to the Record Review Committee a copy of an evaluation report within  
3 fourteen (14) calendar days from the date the evaluator received the evaluation referral;

4 b. If an IFSP is currently in place:

5 (i) Focus recommendations on areas that are specified on the IFSP as being of  
6 concern to the family;

7 (ii) Identify strategies and activities that would help achieve the outcomes  
8 identified on the IFSP; and

9 (iii) Provide suggestions for the discipline most appropriate to transfer the  
10 therapeutic skills to the parents.

11 3. If it is not possible to provide the report and notification required in this  
12 paragraph by the established time frame due to illness of the child or a request by the  
13 parent, the delay circumstances shall be documented.

14 Section 2. Eligibility. (1) A child shall be eligible for First Steps services if he is:

15 (a) Aged birth through two (2) years;

16 (b) A resident of Kentucky at the time of referral and while receiving a service;

17 (c) Through the evaluation process determined to have fallen significantly behind  
18 developmental norms in the following skill areas:

19 1. Total cognitive development;

20 2. Total communication area through speech and language development, which  
21 shall include expressive and receptive;

22 3. Total physical development including growth, vision and hearing;

23 4. Total social and emotional development; or

1           5. Total adaptive skills development; and

2           (d) Is significantly behind in developmental norms as evidenced by the following  
3 criteria:

4           1. Two (2) standard deviations below the mean in one (1) skill area;

5           2. At least one and one-half (1 1/2) standard deviations below the mean in two (2)  
6 skill areas; or

7           3.a. If a norm-referenced testing reveals a delay in one (1) of the five (5) skill areas  
8 but does not meet eligibility criteria, a more in-depth standardized test in that area of  
9 development may be administered if the following is evident:

10           (i) The primary level evaluator, service coordinator or the family has a concern or  
11 suspects that the child's delay may be greater than the testing revealed;

12           (ii) A more sensitive norm-referenced test tool may reveal a standardized score  
13 which would meet eligibility criteria; and

14           (iii) There is one (1) area of development that is of concern.

15           b. Upon completion of the testing established in subparagraph 1. of this paragraph,  
16 the results and information identified in Section 1(8)(b) of this administration shall be  
17 submitted by the service coordinator to the Record Review Team for a determination of  
18 eligibility;

19           (e) Is being cared for by a neonatal follow-up program and its staff determine that  
20 the child meets the eligibility requirements established in paragraphs (a) through (d) or  
21 (f) of this subsection; or

22           (f) Meets the criteria established in KRS 200.654(10)(b) who has one (1) of the  
23 following conditions diagnosed by a physician or advanced registered nurse practitioner

1 (ARNP):

Aase-Smith syndrome
Aase syndrome
Acrocallosal syndrome
Acrodysostosis
Acro-Fronto-Facio-Nasal Dysostosis
Adrenoleukodystrophy
Agenesis of the Corpus Callosum
Agyria
Aicardi syndrome
Alexander's Disease
Alper's syndrome
Amelia
Angelman syndrome
Aniridia
Anophthalmia/Microphthalmia
Antley-Bixler syndrome
Apert syndrome
Arachnoid cyst with neuro-developmental delay
Arhinencephaly
Arthrogryposis
Ataxia

Atelosteogenesis
Autism
Baller-Gerold syndrome
Bannayan-Riley-Ruvalcaba syndrome
Bardet-Biedl syndrome
Bartsocas-Papas syndrome
Beals syndrome (congenital contractural arachnodactyly)
Biotinidase Deficiency
Bixler syndrome
Blackfan-Diamond syndrome
Bobble Head Doll syndrome
Borjeson-Forssman-Lehmann syndrome
Brachial Plexopathy
Brancio-Oto-Renal (BOR) syndrome
Campomelic Dysplasia
Canavan Disease
Carbohydrate Deficient Glycoprotein syndrome
Cardio-Facio-Cutaneous syndrome
Carpenter syndrome
Cataracts - Congenital

Caudal Dysplasia	Cohen syndrome
Cerebro-Costo-Mandibular syndrome	Cone Dystrophy
Cerebellar Aplasia/Hypoplasia/Degeneration	Congenital Cytomegalovirus
Cerebral Atrophy	Congenital Herpes
Cerebral Palsy	Congenital Rubella
Cerebro-oculo-facial-skeletal syndrome	Congenital Syphilis
CHARGE Association	Congenital Toxoplasmosis
Chediak Higashi syndrome	Cortical Blindness
Chondrodysplasia Punctata	Costello syndrome
Christian syndrome	Cri du chat syndrome
Chromosome Abnormality a. unbalanced numerical (autosomal) b. numerical trisomy (chromosomes 1-22) c. sex chromosomes XXX; XXXX; XXXXX;XXXY; XXXXY	Cryptophthalmos
CNS Aneurysm with Neuro-Developmental Delay	Cutis Laxa
CNS Tumor with Neuro Developmental Delay	Cytochrome-c Oxidase Deficiency
Cockayne syndrome	Dandy Walker syndrome
Coffin Lowry syndrome	DeBarsy syndrome
Coffin Siris syndrome	DeBuquois syndrome
	Dejerine-Sottas syndrome
	DeLange syndrome
	DeSanctis-Cacchione syndrome
	Diastrophic Dysplasia
	DiGeorge syndrome (22q11.2 deletion)
	Distal Arthrogyrosis
	Donohue syndrome



Down syndrome	Fetal Hydantoin syndrome
Dubowitz syndrome	Fetal Valproate syndrome
Dygge Melchor-Clausen syndrome	Fetal Varicella syndrome
Dyssegmental Dysplasia	FG syndrome
Dystonia	Fibrochondrogenesis
EEC (Ectrodactyly-ectodermal dysplasia-clefting) syndrome	Floating Harbor syndrome
Encephalocele	Fragile X syndrome
Encephalo-Cranio-Cutaneous syndrome	Fretman-Sheldon (Whistling Facies) syndrome
Encephalomalacia	Fryns syndrome
Exencephaly	Fucosidosis
Facio-Auriculo-Radial dysplasia	Glaucoma - Congenital
Facio-Cardio-Renal (Eastman-Bixler) syndrome	Glutaric Aciduria Type I and II
Familial Dysautonomia (Riley-Day syndrome)	Glycogen Storage Disease
Fanconi Anemia	Goldberg-Shprintzen syndrome
Farber syndrome	Grebe syndrome
Fatty Acid Oxidation Disorder (SCAD, ICAD, LCHAD)	Hallermann-Streiff syndrome
Femoral Hypoplasia	Hays-Wells syndrome
Fetal Alcohol syndrome/Effects	Head Trauma with Neurological Sequelae/Developmental Delay
Fetal Dyskinesia	Hearing Loss (Bilateral permanent hearing loss with pure tone average of 30dB or greater)

Hemimegalencephaly	Incontinentia Pigmenti
Hemiplegia/Hemiparesis	Infantile spasms
Hemorrhage-Intraventricular Grade III, IV	Iniencephaly
Hereditary Sensory & Autonomic Neuropathy	Isovaleric Acidemia
Hereditary Sensory Motor Neuropathy (Charcot Marie Tooth Disease)	Jarcho-Levin syndrome
Herrmann syndrome	Jervell syndrome
Heterotopias	Johanson-Blizzard syndrome
Holoprosencephaly (Aprosencephaly	Joubert syndrome
Holt-Oram syndrome	Kabuki syndrome
Homocystinuria	KBG syndrome
Hunter syndrome (MPSII)	Kenny-Caffey syndrome
Huntington Disease	Klee Blattschadel
Hurler syndrome (MPSI)	Klippel-Feil Sequence
Hyalanosis	Landau-Kleffner syndrome
Hydranencephaly	Lange-Nielsen syndrome
Hydrocephalus	Langer Giedion syndrome
Hyperpipecolic Acidema	Larsen syndrome
Hypomelanosis of ITO	Laurin-Sandrow syndrome
Hypophosphatasia-Infantile	Leber's Amaurosis
Hypoxic Ischemic encephalopathy	Legal blindness (bilateral visual acuity of 20/200 or worse corrected vision in better eye)
I-Cell (mucopolidosis II) Disease	Leigh Disease

Lennox-Gastaut syndrome	Methylmalonic Acidemia
Lenz Majewski syndrome	Microcephaly
Lenz Microphthalmia syndrome	Microtia-Bilateral
Levy-Hollister (LADD) syndrome	Midas syndrome
Lesch-Nyhan syndrome	Miller (postaxial acrofacial-Dysostosis) syndrome
Leukodystrophy	Miller-Dieker syndrome
Lissencephaly	Mitochondrial Disorder
Lowe syndrome	Moebius syndrome
Lowry-Maclean syndrome	Morquio syndrome (MPS IV)
Maffucci syndrome	Moya-Moya Disease
Mannosidosis	Mucopolidosis II, III
Maple Syrup Urine Disease	Multiple congenital anomalies (major organ birth defects)
Marden Walker syndrome	Multiple Pterygium syndrome
Marshall syndrome	Muscular Dystrophy
Marshall-Smith syndrome	Myasthenia Gravis - Congenital
Maroteaux-Lamy syndrome (MPS VI)	Myelocystocele
Maternal PKU Effects	Myopathy - Congenital
Megalencephaly	Myotonic Dystrophy
MELAS	Nager (Acrofacial Dysostosis) syndrome
Meningocele (cervical)	Nance Horan syndrome
MERRF	NARP
Metachromatic Leukodystrophy	
Metatropic Dysplasia	

Neonatal Meningitis/Encephalitis	Pierre Robin Sequence
Neuronal Ceroid Lipofuscinoses	Poland Sequence
Neuronal Migration Disorder	Polymicrogyria
Nonketotic Hyperglycinemia	Popliteal Pterygium syndrome
Noonan syndrome	Porencephaly
Ocular Albinism	Prader-Willi syndrome
Oculocerebrocutaneous syndrome	Progeria
Oculo-Cutaneous Albinism	Propionic Acidemia
Optic Atrophy	Proteus syndrome
Optic Nerve Hypoplasia	Pyruvate carboxylase Deficiency
Oral-Facial-Digital syndrome Type I-VII	Pyruvate Dehydrogenase Deficiency
Osteogenesis Imperfecta Type III-IV	Radial Aplasia/Hypoplasia
Osteopetrosis (Autosomal Recessive)	Refsum Disease
Oto-Palato-Digital Syndrome Type I-II	Retinoblastoma
Pachygyria	Retinoic Acid Embryopathy
Pallister Mosaic syndrome	Retinopathy of Prematurity Stages III, IV
Pallister-Hall syndrome	Rett syndrome
Pelizaeus-Merzbacher Disease	Rickets
Pendred's syndrome	Rieger syndrome
Periventricular Leukomalacia	Roberts SC Phocomelia
Pervasive Developmental Disorder	Robinow syndrome
Peters Anomaly	Rubinstein-Taybi syndrome
Phocomelia	Sanfilippo syndrome (MPS III)

Schinzel-Giedion syndrome	syndrome)
Schimmelpenning syndrome (Epidermal Nevus syndrome)	Thanatophoric Dysplasia
Schizencephaly	Tibial Aplasia (Hypoplasia)
Schwartz-Jampel syndrome	Toriello-Carey syndrome
Seckel syndrome	Townes-Brocks syndrome
Septo-Optic Dysplasia	Treacher-Collins syndrome
Shaken Baby syndrome	Trisomy 13
Short syndrome	Trisomy 18
Sialidosis	Tuberous Sclerosis
Simpson-Golabi-Behmel syndrome	Urea Cycle Defect
Sly syndrome (MPS VII)	Velocardiofacial syndrome (22q11.2 deletion)
Smith-Fineman-Myers syndrome	Wildervanck syndrome
Smith-Limitz-Opitz syndrome	Walker-Warburg syndrome
Smith-Magenis syndrome	Weaver syndrome
Sotos syndrome	Wiedemann-Rautenstrauch syndrome
Spina Bifida (Meningomyelocele)	Williams syndrome
Spinal Muscular Atrophy	Winchester syndrome
Spondyloepiphyseal Dysplasia Congenita	Wolf Hirschhorn syndrome
Spondylometaphyseal Dysplasia	Yunis-Varon syndrome
Stroke	Zellweger syndrome
Sturge-Weber syndrome	
TAR (Thrombocytopenia-Absent Radii	

1 (2) If a child referred to the First Steps Program was born at less than thirty-seven  
2 (37) weeks gestational age, the following shall be considered:

3 (a) The chronological age of infants and toddlers who are less than twenty-four  
4 (24) months old shall be corrected to account for premature birth. The evaluator shall  
5 ensure that the instrument being used allows for the adjustment for prematurity. If it  
6 does not, another instrument shall be used.

7 (b) Correction for prematurity is not appropriate for children born prematurely  
8 whose chronological age is twenty-four (24) months or greater.

9 (c) Documentation of prematurity shall include a physician's or nurse practitioner's  
10 written report of gestational age and a brief medical history.

11 (d) Evaluation reports on premature infants and toddlers shall include test scores  
12 calculated with the use of both corrected and chronological ages.

13 Section 3. Incorporation by Reference. (1) The Early, Periodic, Screening,  
14 Diagnostic and Treatment (EPSDT) Periodicity Schedule, edition, is incorporated by  
15 reference.

16 (2) This material may be inspected, copied or obtained, subject to applicable  
17 copyright law, at the Commission for Children with Special Health Care Needs, 982  
18 Eastern Parkway, Louisville, Kentucky 40217, Monday through Friday, 8 a.m. to 4:30  
19 p.m.

20 Section 4. The provisions of this administrative regulation shall be effective with  
21 services provided on or after January 1, 2004.